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Chapter 10

Perspectives on the Patient Experience (PX) of People with Disabilities in the Digital Age: From UX to PX

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10.1. Introduction

User-centered approaches, in the sense of Norman (1986) or of the ISO 9241-210: 2019 standard, need to now be used systematically for any design or improvement of healthcare systems. It is indeed important that the patient is considered as a real actor with regards to their own healthcare journey. In addition, it is about providing easy access to the hospital's digital services and optimizing the flow of information between the different hubs or health sectors, and therefore between different actors within the organization. These accesses concern different contexts: before, during and after the care of the patient, in order to allow patients to have, in particular, a good digital experience or an adapted way of living with technology. This is generally called User eXperience (UX), which has been the subject of much research and many proposals (Alben, 1996; Hassenzahl and Tractinsky, 2006). This digital experience concerns doctors, nursing and hospital staff, patients, caregivers, partners and health service institutions. This is referred to as the Patient eXperience or PX (AHRQ, 2017).

A problem arises concerning patients with disabilities (AHRQ, 2019), whose needs are specific, and which can vary widely according to their type of disability, and who can live very restrictive and different digital experiences. Different types of questions arise: what types of access devices and what services could be put in place to improve the experience of this patient category? For example, making an appointment and going to the hospital can cause different types of problems depending on the type of disability. In addition, regarding the reception at the hospital, when a patient arrives, they usually have to take a ticket at a terminal. This action sounds simple for an able-bodied person, but may be difficult for a person with a motor impairment.

In this regard, within the field of disability, there are numerous disabilities organized into several categories: physical, mental and psychological (Winance, 2008). Each category is usually made up of dozens of different disabilities, each with its own characteristics. Each person with a disability therefore has specific needs in

relation to the systems to be used. For example, a blind person will not have the same needs as an upper or lower limb amputee. It is therefore important to take into account user experience (UX) in general, and patient experience (PX), for our case in particular, in the design of an interactive system or a health process that includes digital services. However, sometimes the capture of user needs encounters difficulties for the design of systems dedicated to people with disabilities with different types of disorders: communication, motor, cognitive, etc. (Antona *et al.*, 2009).

In this chapter, we deal with the dimension of the digitization of the healthcare journey aiming as experienced by a patient with a disability. This refers in part to the Web Accessibility Initiative (WAI), as web services can help improve health journeys. This presents a set of challenges. These relate to the technical and methodological preparations to be considered when developing digital services focused on patients with disabilities and which must be dealt with as early as possible (Altinier, 2012). It is with this in mind that we are proposing a first approach to developing this patient experience which will integrate the various stakeholders (patients, accompanying persons, hospital or medical staff, and health professionals), while identifying new uses linked to the healthcare journey of patients with disabilities.

This approach aims to take into account the web accessibility recommendations and criteria described by: Web Content Accessibility Guidelines (WCAG), User Agent Accessibility Guidelines (UAAG), and Authoring Tool Accessibility Guidelines (ATAG).

10.2. State-of-the-Art on Patient eXperience (PX)

User eXperience (UX), for which examples of implementation can be found in numerous documents, including those of Touloum *et al.* (2012), Gube (2010) or (Komminos, 2019), and deals with the way in which a user interacts with a system and how this experience is felt. In this area, there are many ways to capture user experience, such as through questionnaires or focus groups (Lallemant and Gronier, 2018).

As we can see in Figure 10.1, adapted from Lallemant and Gronier (2018), in general, the design of an application or a good takes place in several stages. Stage 1 is the planning stage (the definition of the objectives of a project and reflection on the tools and resources necessary for the projects). Step 2 is devoted to exploration (collecting user needs). Step 3 is the ideation phase (summary of the exploration phase and production of ideas for the design). The purpose of Step 4 is generation (the formalization of design solution(s)). Lastly, Step 5 is devoted to the iterative evaluation of the solutions generated. We can clearly see in Figure 10.1 that this process is iterative: this means that there are usually several *back-and-forths* between the different phases. Thanks to these *back-and-forths*, the designer places the future user at the center of development in order to better meet the requirements.

More specifically, in the area of disability and user-centered design, it is about highlighting an important theme to determine the ecosystem of the person with a disability. Depending on the case and the type of disability, the ecosystem may be comprised of the disabled person using the system, the accompanying person who may be either a family member or a professional, different people with whom they will be interacting with, the likely assistance tools; this ecosystem can in fact vary enormously depending on the context (Sauzin, 2017; Guffroy *et al.*, 2017; 2018). Ecosystem actors can most often help define the user's needs for the design of their future system(s). To better understand this, we cite as an example the communication aid called ComMob (Guerrier, 2015). This software tool was developed by the third author of this chapter: Yohan Guerrier. It allows sentences to be formulated from pictograms which are organized by category and theme. In this case, the ecosystem was made up of the user, their caregiver, and ComMob, as well as various counterparts, known or unknown *a priori*, which may vary depending on the context (for example, if the user is mobility). During the development of this application, the needs of the user were expressed both by the designer, who is himself disabled, and by various caregivers; field evaluations were also carried out in the presence of counterparts unknown *a priori* (Guerrier *et al.*, 2014).

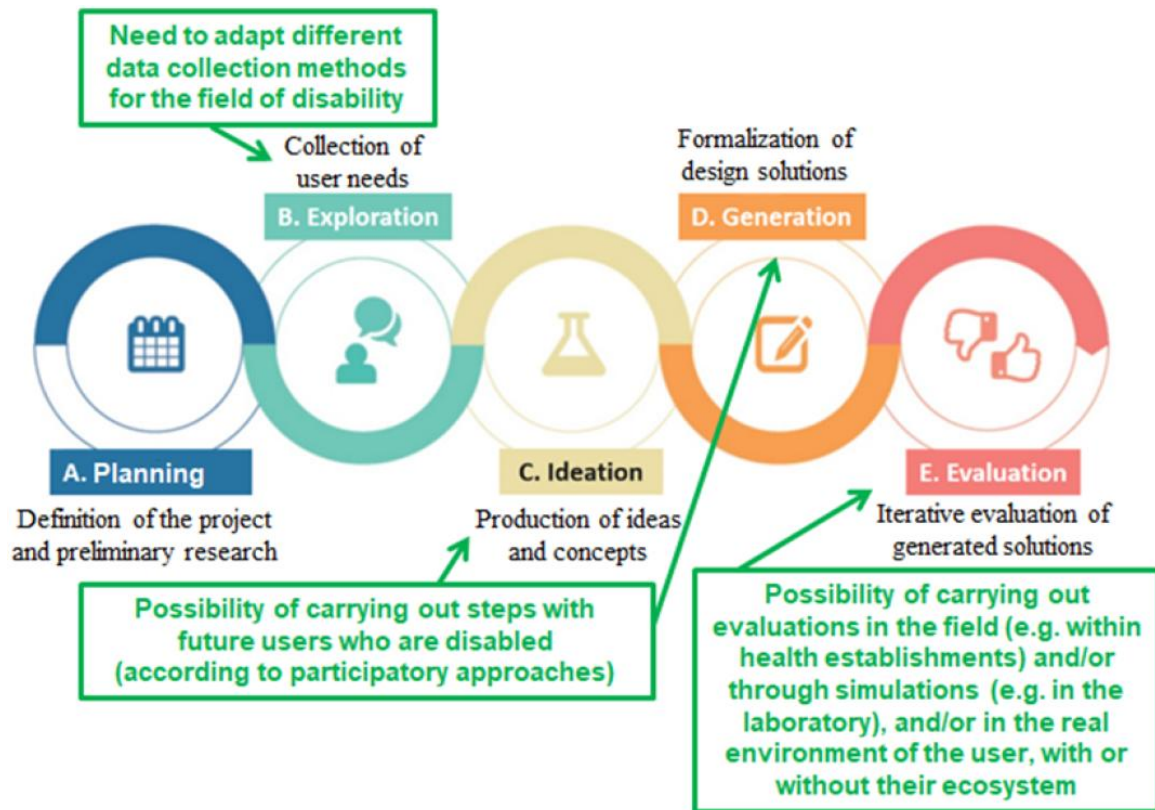


Figure 10.1. Iterative design cycle of interactive systems (adapted from Lallemand and Gronier, 2018, with various additions in green related to the field of disability)

After defining the user experience theme, it is time to apply it to the medical field. Patient eXperience (AHRQ, 2017) includes all of the interactions that patients can have with a healthcare system and which may include their doctors, nurses, healthcare practitioners, etc. As an integral component of the healthcare quality system, PX includes several aspects of healthcare delivery that patients expect when seeking and receiving care, such as scheduling appointments, accessing information, and better communication with their counterparts, wherever they are located, both inside and outside health establishments.

Disabled patients for whom the PX is different and restrictive, require an adapted approach to meet their specific needs, in conjunction with appropriate digital services. Thus, when we consider the different aspects of PX, we can assess the extent to which patients receive associated care and services, appropriate and customizable to individual characteristics, preferences, needs and expectations. In addition, evaluating PX with other components such as the efficiency and safety of healthcare is essential to convey a holistic view of the quality of care being provided. Therefore, understanding PX is a key step towards patient-centered healthcare. Various methods to collect information on PX are provided by the specialized literature, see for example: the Consumer Assessment of Healthcare Providers and Systems or CAHPS (AHRQ, 2017).

In recent years, a growing interest from academia and industry has enriched the concept of PX, placing greater import on the latter with regards to the constant endeavor to improve the quality of healthcare provided and reducing costs. PX is becoming a key factor in the healthcare revolution. In contrast, little tangible field work has been undertaken in PX in the digital age. To this end, the objective of the digital transformation of the patient journey through all assistive technologies (Altinier, 2012 & 2019; W3C, 2017) is to ensure the continuity and improvement of care at each stage of the patient journey, which has been enhanced thanks to the associated digital tools, by means of multiplatform access, capable of improving the patient experience on the one hand and of modifying the practices of healthcare professionals on the other, as shown in Figure 10.2.

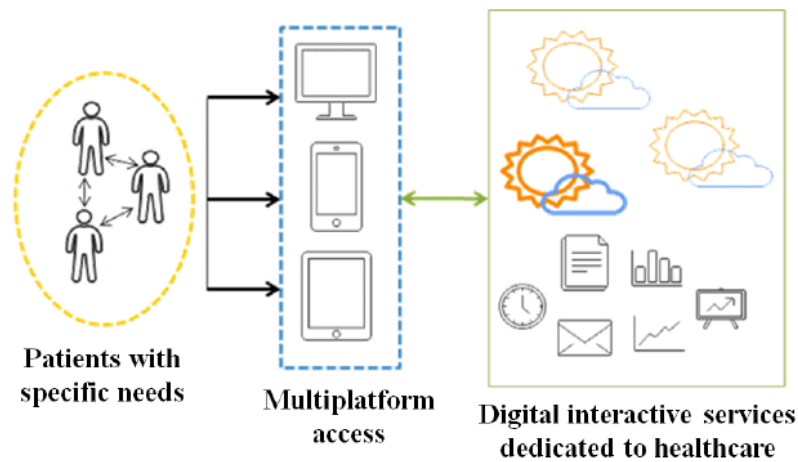


Figure 10.2. General view of the digital health concept.

10.3. Research Methodology & Proposal

This involves proposing a methodological framework (see Figure 10.3) for the development of the Patient eXperience for people with specific needs during their care journey, while taking into account the recommendations and criteria for web accessibility stated in WCAG2, adapted from W3C (W3C, 2017) and AccessiWeb (Altinier, 2019). While having common concepts with the classic user-centered design, within the meaning of Norman (1986; 2013), or as described in the ISO standard (where the needs, expectations and specific characteristics of end users are taken into account at each step of the product development process; this approach being based on the idea that end users are best placed to express their own needs, and thus should participate in the design, evaluation and use of the interactive system, up until the needs and requirements expressed by users are satisfied), in participatory design (Schuler and Namioka, 1993; Kensing, 2003) and the “Design for All” approach (Stephanidis and Salvendy, 1998; Stephanidis, 2001); the proposal consists of in some way going further, insofar as we do not focus on a system, but on a complete progression, considering very different situations, from the points of view of a set of actors, and possibly requiring a set of systems. In each situation to be taken into account, the ecosystem of the patient with a disability will be considered with great consideration (as emphasized above).

The conceptual framework is based on the *Design Thinking* approach, which is an innovation management method, promoting so-called creative or collaborative design, based on a (non-linear) process of co-creativity involving the user final; see for example (Gibbons, 2016; Interaction Design Foundation; KLAP; D. SCHOOL). Referring to (Gibbons, 2016), it follows the global flow to “Understand, Explore, and Materialize” and is broken down into 6 phases: (1) Analyze and Study, (2) Define, (3) Imagine, (4) Prototype, (5) Test, and (6) Implement. The UX deliverables (Komminos, 2019) of each phase may vary depending on the roles of the project team on the one hand, and on the methods and tools used by each role on the other (Figure 10.3). The actors who can be involved in the process of developing and delivering the Patient eXperience, with a focus on quality, for people with specific needs can be greatly varied depending on the healthcare journey concerned, including in addition to patients (and their possible companions, members of their ecosystem) and actors encountered on the journey (medical secretariats, health personnel, etc.), specialists in UX, PX and Human-Computer Interaction (HCI), members of software development teams, other various players from different fields (marketing, insurance, security, etc.) (see Figure 10.3).

The first two phases generally grouped under the term “User Research” consist in acquiring a deeper understanding of the problem(s) and needs to be resolved in relation to the profiles of the actors concerned. The deliverables of this phase can be visualized and synthesized through different types of methods taken from the UX field: personas (Cooper, 1999; Seffah *et al.*, 2009; Brangier and Bornet, 2011; Idoughi *et al.*, 2012; Göltz, 2014), storyboards (Krause, 2018) and the *Patient Journey Map* approach, the latter being derived directly from

the *Customer Journey Map* (or *Experience Map*) approach (Shostack, 1977; Komminos, 2019). Note that other UX methods could be exploited, as illustrated by Lallemand and Gronier (2018).

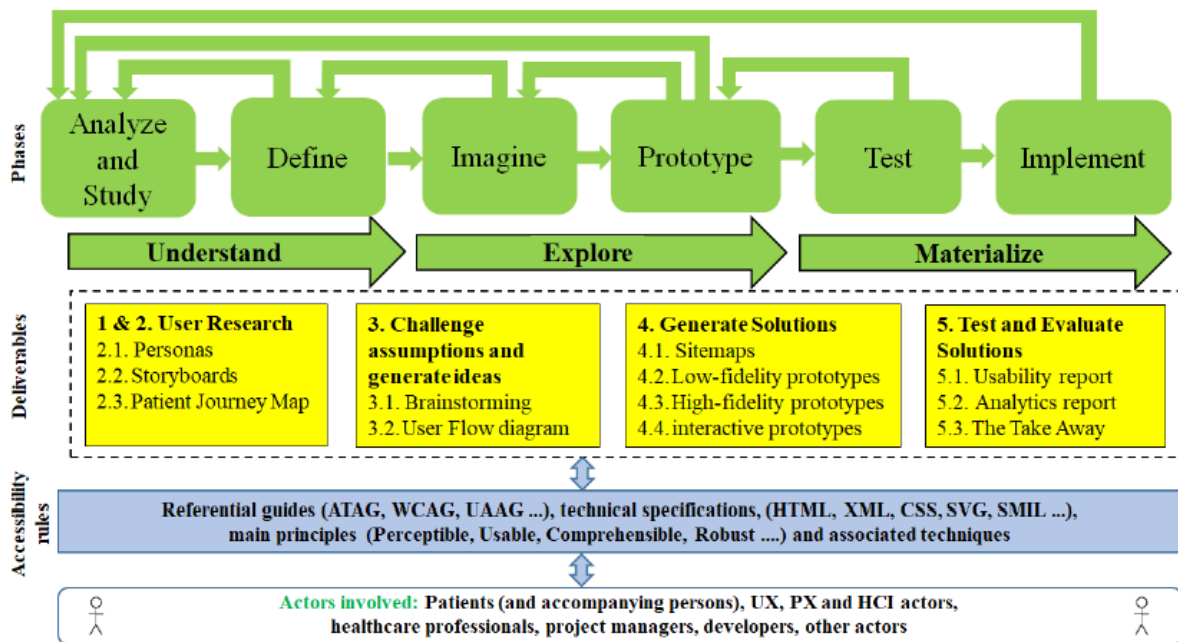



Figure 10.3. Global view of the development methodological framework (inspired and adapted from (Gibbons, 2016)).

10.4. Illustrations Relating to the “User research” Phase of the Methodological Framework

In the “User Research” phase of the methodological framework, we propose to first use the Persona technique, situated upstream of other patient-centered research methods, in order to understand the specific or underlying needs of people with disabilities, and their modes of using the web and associated digital technologies. This is an essential prerequisite to meeting the accessibility standards, in the broad sense, for all types of patient journey.

Starting from the principle that it is based on a set of personas covering a representative set of categories of disabled persons, Figure 10.4 illustrates a persona characterized by a data set relating to his or her situation, handicap, of the cerebral palsy type, expressing their motivations, objectives, needs and expectations in relation to the use of digital technology in the context of their healthcare strategy, while highlighting their constraints and obstacles.



Alain is a researcher in the field of Marine Biology. He works in a laboratory located in the Hauts-de-France region, in France. He is 42 years old, married and the father of 2 children.

Alain uses a communication aid on a daily basis, consisting of pictogram-based software accessed via the tablet on his wheelchair. Alain has cerebral palsy and as such makes involuntary movements, limited in number and low in terms of intensity.

His goal has always been to communicate as easily as possible with those around him, for both personal and professional interactions. According to him, you cannot be integrated into society without being able to communicate easily. Thanks to his communication aid, he can organize meetings within the laboratory with his colleagues, even in different languages.

On a personal level, Alain has always had difficulty making medical appointments due to his speech impediments and needs to ask a third party in order to call a doctor. In addition, during the meetings, he must be accompanied so that the person repeats his remarks to the professional. Finally, Alain cannot pay for the consultations himself because of his involuntary movements.

Alain has encountered difficulties throughout his life due to his disability. The medical profession regularly takes him for a person with a mental disability. The doctor speaks to the person accompanying him instead of speaking directly to Alain.

In this context, Alain would like specific IT help from the medical field to enable him to communicate directly with the practitioner on his own. In addition, he would like a tool to enable him to make his own medical appointments without going through an intermediary.

Alain interacting with the tablet installed on his wheelchair

Figure 10.4. *Persona: Alain*

Next, by considering disability as a source of innovation, it is possible to proceed through storyboards (Krause, 2018) through which the actions of the user and the circumstances in which they are carried out are described or represented (Figure. 10.5).

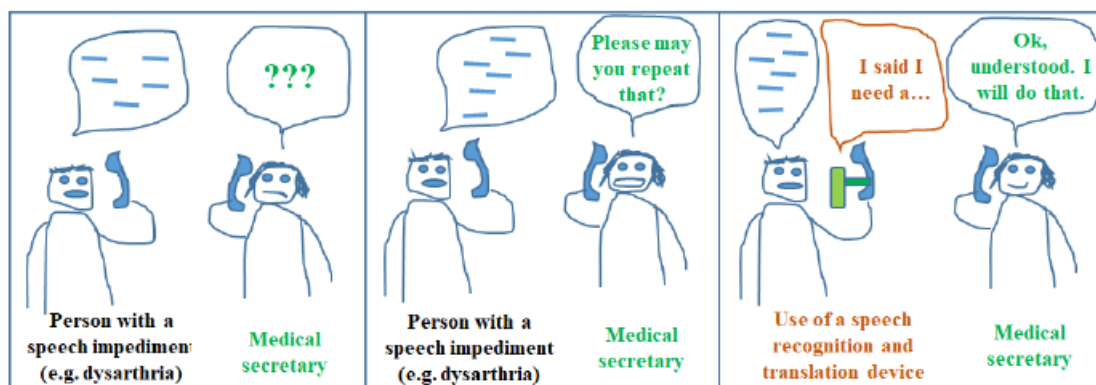


Figure 10.5. *Principle of holistic visualization through storyboards of the actions of disabled persons and the technological / digital environment in which they can take place, with a view to orient towards design choices / decision-making.*

An *eXperience Map* is a diagram representing the steps in the process undertaken by the user in order to accomplish a task or to achieve a goal (Komminos, 2019). This will allow the designer to understand the changes in terms of the context, in addition to the motivations, issues and needs encountered throughout the process, as illustrated in the case study below.

10.5. Case study: Digital Care Journey of a Patient with a Disability

The Patient eXperience journey mapping is a technique for understanding the motivations, needs, hesitations and concerns of patients. It uses visuals and narratives to illustrate the different relationships and interactions that a patient can have with a digital service over a period of time. The narration is expressed from the point of view of the patient, who for our example is disabled; this patient describes in detail his experience with the digital service offered. This narration helps the project / development team to observe concretely and holistically the healthcare journey of a patient. The Patient eXperience journey is organized into stages, each representing a particular goal that the patient with a disability wants to achieve along their healthcare journey. The steps correspond to a goal-oriented and non-process-oriented healthcare journey. Therefore, in order to create the Patient eXperience Map, we need to consider some relevant questions, such as: (1) How do patients behave in a situation upstream of the implementation of the proposed solution or service? (2) What is the patient problem to be solved, in other words, what are the critical or constraining points that the patient wants to see improved or overcome? (3) How to improve patient engagement through various communication channels and digital media? Depending on the context and type of disability concerned, the use of a communication support system may be necessary; for further reading on this subject and the different system categories of this type see Guerrier *et al.* (2018).

The uses linked to the healthcare journey for patients with disabilities may concern patients, caregivers as well as hospital or medical staff; Remember that we can also speak of the ecosystem of the disabled person, as described by Guffroy *et al.*, (2017), mentioned above. For example, the Patient eXperience services can be as follows: (1) Messaging Services (medical team messages, upstream or downstream healthcare messages, other messages, etc.), (2) Alert Services (receiving medication reminders, making an appointment, etc.), (3) Planning and Diary Services (management of appointments, planning, etc.), (4) Instruction and Training Services (help with training or education), (5) Emergency Healthcare Notifications, etc. In fact, all the services listed above correspond to the different points of contact that the patient may encounter when interacting with their real and digital environments. A very simplified example of an eXperience map, illustrating the patient journey desire to make their own monthly appointment for a medical check-up, is provided by the graphic shown in Figure 10.6; see (Lallemand and Gronier, 2018) for more detailed illustrations.

The patient achieves a particular goal at the end of each step of the healthcare journey corresponding to the contact points of the following services: (1) Contacting consultation services, (2) Consideration of the list of doctors after diagnosis, (3) Discussion with medical professionals, (4) Making an appointment with a suitable doctor. Once the goals and points of contact have been identified and understood, and each stage of the CXP has been covered with the project team, one must successfully identify the potential points of friction and possible difficulties that have or may be encountered and which must be resolved, with a view to improving PX.

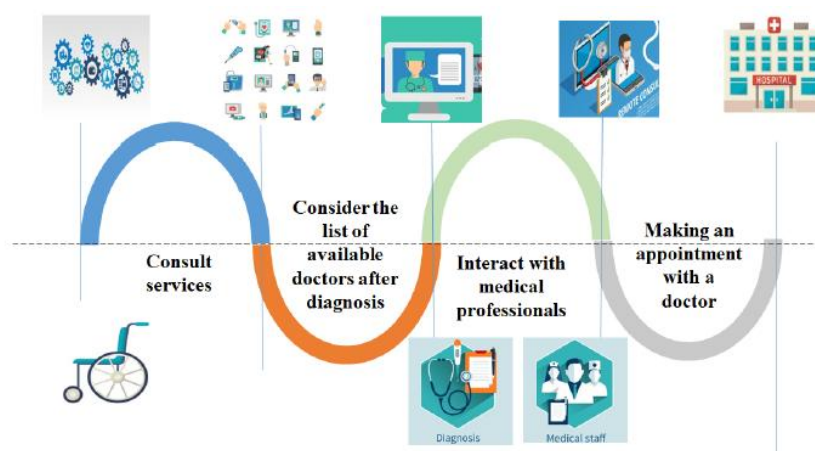


Figure 10.6. Example of an eXperience map for an “appointment book” patient journey (inspired by Lee *et al.*, 2015; Touloum *et al.*, 2018; and Touloum, 2019).

10.6. Conclusion

We have described and positioned the importance of the patient eXperience (PX) in a patient-centered development approach aiming for an advanced medical management of a patient. We have focused on patients with disabilities for whom the patient experience may be different and constraining, requiring an adapted approach in order to link their specific needs with the appropriate digital services. Our approach is primarily based on the *Design Thinking* approach which is appropriate for the type of problem we are dealing with in this research. It is an innovative methodology that transforms ideas and projects into real activities and tangible prototypes. Certain challenges, in particular those facing UX designers, graphic designers, project managers or even software engineers may on the one hand be encountered, whilst on the other, the challenges facing patients with specific needs, as well as those of their associated healthcare professionals and medical staff, may be encountered and likewise developed.

Each phase of the process is iterative and cyclical as opposed to being a strictly linear process. In addition, we can also go back to the first two phases “Analyze and Study” and “Define” after the development and testing of the initial prototype. Several illustrations associated with the methodological approach have been provided, thus giving a representative overview of the richness and potential of the approach.

There are many research perspectives. Indeed, given the issues formulated in the form of scenarios related to health and more particularly to patient journeys, in its interaction with various people involved in the rapid development of the first digital PX services, it is now a question of highlighting the application of this approach in the form of workshops. These would have both design and evaluation goals focusing on the improvement of patient pathways, wherein the participants would try to make concrete the innovative ideas expressed and test them with disabled persons, and their possible companions (actors within their ecosystem), in the context of real or simulated situations.

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